# SUBCHAPTER I—THE ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, DEVELOPMENTAL DISABILITIES PROGRAM

### PART 1385—REQUIREMENTS APPLI-CABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAM

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Authority: 42 U.S.C. 15001 et seq.

Source:  $80 \ \mathrm{FR} \ 44807$ , July 27, 2015, unless otherwise noted.

### §1385.1 General.

Except as specified in §1385.4, the requirements in this part are applicable to the following programs and projects:

- (a) Federal Assistance to State Councils on Developmental Disabilities;
- (b) Protection and Advocacy for Individuals with Developmental Disabilities:
- (c) Projects of National Significance; and
- (d) National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

### § 1385.2 Purpose of the regulations.

These regulations implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 *et seq.*).

### § 1385.3 Definitions.

For the purposes of parts 1385 through 1388 of this chapter, the following definitions apply:

ACL. The term "ACL" means the Administration for Community Living within the U.S. Department of Health and Human Services.

Act. The term "Act" means the Developmental Disabilities Assistance

and Bill of Rights Act of 2000 (DD Act of 2000) (42 U.S.C.  $15001 \ et \ seq.$ ).

Accessibility. The term "Accessibility" means that programs funded under the DD Act of 2000 and facilities which are used in those programs meet applicable requirements of section 504 of the Rehabilitation Act of 1973 (Pub. L. 93–112), its implementing regulation, 45 CFR part 84, the Americans with Disabilities Act of 1990, as amended, Title VI of the Civil Rights Act of 1964 (Pub. L. 88–352), and its implementing regulation, 45 CFR part 80.

- (1) For programs funded under the DD Act of 2000, information shall be provided to applicants and program participants in plain language and in a manner that is accessible and timely to:
- (i) Individuals with disabilities, including accessible Web sites and the provision of auxiliary aids and services at no cost to the individual; and
- (ii) Individuals who are limited English proficient through the provision of language services at no cost to the individual, including:
  - (A) Oral interpretation;
  - (B) Written translations; and
- (C) Taglines in non-English languages indicating the availability of language services.

AIDD. The term "AIDD" means the Administration on Intellectual and Developmental Disabilities, within the Administration for Community Living at the U.S. Department of Health and Human Services.

Advocacy activities. The term "advocacy activities" means active support of policies and practices that promote systems change efforts and other activities that further advance self-determination and inclusion in all aspects of community living (including housing, education, employment, and other aspects) for individuals with developmental disabilities, and their families.

Areas of emphasis. The term "areas of emphasis" means the areas related to quality assurance activities, education

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activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

Assistive technology device. The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities.

Assistive technology service. The term "assistive technology service" means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes: Conducting an evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual's customary environment; purchasing, leasing, or otherwise providing for the acquisition of an assistive technology device by an individual with a developmental disability; selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing an assistive technology device; coordinating and using another therapy, intervention, or service with an assistive technology device, such as a therapy, intervention, or service associated with an education or rehabilitation plan or program; providing training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and providing training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of, an individual with developmental disabilities.

Capacity building activities. The term "capacity building activities" means

activities (e.g. training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life.

Center. The term "Center" means a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) established under subtitle D of the Act.

Child care-related activities. The term "child care-related activities" means advocacy, capacity building, and systemic change activities that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities

Culturally competent. The term "culturally competent," used with respect to services, supports, and other assistance means that services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

Department. The term "Department" means the U.S. Department of Health and Human Services.

Developmental disability. The term "developmental disability" means a severe, chronic disability of an individual that:

- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (2) Is manifested before the individual attains age 22:
  - (3) Is likely to continue indefinitely;
- (4) Results in substantial functional limitations in three or more of the following areas of major life activity:
  - (i) Self-care;
- (ii) Receptive and expressive language;
  - (iii) Learning;
  - (iv) Mobility;
- (vi) Self-direction;

(vii) Capacity for independent living; and

(viii) Economic self-sufficiency.

(5) Reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Early intervention activities. The term "early intervention activities" means advocacy, capacity building, and systemic change activities provided to infants and young children described in the definition of "developmental disability" and their families to enhance the development of the individuals to maximize their potential, and the capacity of families to meet the special needs of the individuals.

Education activities. The term "education activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life.

Employment-related activities. The term "employment-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

Family support services. The term "family support services" means services, supports, and other assistance, provided to families with a member or members who have developmental disabilities, that are designed to:

Strengthen the family's role as primary caregiver; prevent inappropriate out-of-the-home placement of the members and maintain family unity; and reunite, whenever possible, families with members who have been placed out of the home. This term includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses associated with the needs of individuals with developmental disabilities.

Fiscal year. The term "fiscal year" means the Federal fiscal year unless otherwise specified.

Governor. The term "Governor" means the chief executive officer of a State, as that term is defined in the Act, or his or her designee who has been formally designated to act for the Governor in carrying out the requirements of the Act and the regulations.

Health-related activities. The term "health-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.

Housing-related activities. The term "housing-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

Inclusion. The term "inclusion", used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enable individuals with developmental disabilities to have friendships and relationships with individuals and families of their own

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choice; live in homes close to community resources, with regular contact with individuals without disabilities in their communities; enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

Individualized supports. The term "individualized supports" means supports that: Enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life; designed to enable such individual to control such individual's environment, permitting the most independent life possible; and prevent placement into a more restrictive living arrangement than is necessary and enable such individual to live, learn, work, and enjoy life in the community; and include early intervention services, respite care, personal assistance services, family support services, supported employment services support services for families headed by aging caregivers of individuals with developmental disabilities, and provision of rehabilitation technology and assistive technology, and assistive technology services.

Integration. The term "integration," means exercising the equal rights of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

Not-for-profit. The term "not-for-profit," used with respect to an agency, institution or organization, means an agency, institution, or organization that is owned or operated by one or more corporations or associations, no part of the net earnings of which injures, or may lawfully inure, to the benefit of any private shareholder or individual.

Personal assistance services. The term "personal assistance services" means a range of services provided by one or more individuals designed to assist an individual with a disability to perform

daily activities, including activities on or off a job, that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual's control in life and ability to perform everyday activities, including activities on or off a job.

Prevention activities. The term "prevention activities" means activities that address the causes of developmental disabilities and the exacerbation of functional limitation, such as activities that: Eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that increase the prevalence of developmental disabilities; increase the early identification of problems to eliminate circumstances that create or increase functional limitations: and mitigate against the effects of developmental disabilities throughout the lifespan of an individual.

Productivity. The term "productivity" means engagement in incomeproducing work that is measured by increased income, improved employment status, or job advancement, or engagement in work that contributes to a household or community.

Protection and Advocacy (P&A) Agency. The term "Protection and Advocacy (P&A) Agency" means a protection and advocacy system established in accordance with section 143 of the

Quality assurance activities. The term "quality assurance activities" means advocacy, capacity building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection that include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and will not be subject to the inappropriate use of restraints or seclusion; include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and

their guardians to ensure that those individuals will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and will not be subject to the inappropriate use of restraints or seclusion; or include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life of individuals with developmental disabilities.

Rehabilitation technology. The term "rehabilitation technology" means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by individuals with developmental disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation. Such term includes rehabilitation engineering, and the provision of assistive technology devices and assistive technology services.

Required planning documents. The term "required planning documents" means the State plans required by \$1386.30 of this chapter for the State Council on Developmental Disabilities, the Annual Statement of Goals and Priorities required by \$1386.22(c) of this chapter for P&As, and the five-year plan and annual report required by \$1388.7 of this chapter for UCEDDs.

Secretary. The term "Secretary" means the Secretary of the U.S. Department of Health and Human Services.

Self-determination activities. The term "self-determination activities" means activities that result in individuals with developmental disabilities, with appropriate assistance, having the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and con-

tribute to, their communities; and support, including financial support, to advocate for themselves and others to develop leadership skills through training in self-advocacy to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

State. The term "State":

- (1) Except as applied to the University Centers of Excellence in Developmental Disabilities Education, Research and Service in section 155 of the Act, includes each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.
- (2) For the purpose of UCEDDs in section 155 of the Act and part 1388 of this chapter, "State" means each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, and Guam.

State Council on Developmental Disabilities (SCDD). The term "State Council on Developmental Disabilities (SCDD)" means a Council established under section 125 of the DD Act.

Supported employment services. The term "supported employment services" means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

Systemic change activities. The term "systemic change activities" means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

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Transportation-related activities. The term "transportation-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

UCEDD. The term "UCEDD" means University Centers for Excellence in Developmental Disabilities Education, Research, and Service, also known by the term "Center" under section 102(5) of the Act.

Unserved and underserved. The term "unserved and underserved" includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in community life.

# § 1385.4 Rights of individuals with developmental disabilities.

- (a) Section 109 of the Act, Rights of Individuals with Developmental Disabilities (42 U.S.C. 15009), is applicable to the SCDD.
- (b) In order to comply with section 124(c)(5)(H) of the Act (42 U.S.C. 15024(c)(5)(H)), regarding the rights of individuals with developmental disabilities, the State participating in the SCDD program must meet the requirements of 45 CFR 1386.30(f).
- (c) Applications from UCEDDs also must contain an assurance that the human rights of individuals assisted by this program will be protected consistent with section 101(c) (see section 154(a)(3)(D) of the Act).

### §1385.5 [Reserved]

### § 1385.6 Employment of individuals with disabilities.

Each grantee which receives Federal funding under the Act must meet the requirements of section 107 of the Act (42 U.S.C. 15007) regarding affirmative action. The grantee must take affirmative action to employ and advance in employment and otherwise treat quali-

fied individuals with disabilities without discrimination based upon their physical or mental disability in all employment practices such: Advertising, recruitment, employment, rates of pay or other forms of compensation, selection for training, including apprenticeship, upgrading, demotion or transfer, and layoff or termination. This obligation is in addition to the requirements of 45 CFR part 84, subpart B, prohibiting discrimination in employment practices on the basis of disability in programs receiving assistance from the Department. Recipients of funds under the Act also may be bound by the provisions of the Americans with Disabilities Act of 1990 (Pub. L. 101-336, 42 U.S.C. 12101 et seq.) with respect to employment of individuals with disabilities. Failure to comply with section 107 of the Act may result in loss of Federal funds under the Act. If a compliance action is taken, the State will be given reasonable notice and an opportunity for a hearing as provided in subpart E of 45 CFR part 1386.

### § 1385.7 Reports to the Secretary.

All grantee submission of plans, applications and reports must label goals, activities and results clearly in terms of the following: Area of emphasis, type of activity (advocacy, capacity building, systemic change), and categories of measures of progress.

### § 1385.8 Formula for determining allotments.

The Secretary, or his or her designee, will allocate funds appropriated under the Act for the State Councils on Developmental Disabilities and the P&As as directed in sections 122 and 142 of the Act (42 U.S.C. 15022 and 15042).

## § 1385.9 Grants administration requirements.

- (a) The following parts of this title and title 2 CFR apply to grants funded under parts 1386 and 1388 of this chapter, and to grants for Projects of National Significance under section 162 of the Act (42 U.S.C. 15082):
- (1) 45 CFR part 16—Procedures of the Departmental Grant Appeals Board.
- (2) 45 CFR part 46—Protection of Human Subjects.

- (3) 45 CFR part 75—Uniform Administrative Requirements, Cost Principles, and Audit Requirements for HHS Award.
- (4) 2 CFR part 376—Nonprocurement Debarment and Suspension.
- (5) 45 CFR part 80—Nondiscrimination under Programs Receiving Federal Assistance through the Department of Health and Human Services Effectuation of title VI of the Civil Rights Act of 1964.
- (5) 45 CFR part 81—Practice and Procedure for Hearings under part 80 of this title.
- (6) 45 CFR part 84—Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving Federal Financial Assistance.
- (7) 45 CFR part 86—Nondiscrimination on the Basis of Sex in Education Programs and Activities Receiving Federal Financial Assistance.
- (8) 45 CFR part 91—Nondiscrimination on the Basis of Age in Programs or Activities Receiving Federal Financial Assistance from HHS.
- (9) 45 CFR part 93—New Restrictions on Lobbying.
- (b) The Departmental Appeals Board also has jurisdiction over appeals by any grantee that has received grants under the UCEDD programs or for Projects of National Significance. The scope of the Board's jurisdiction concerning these appeals is described in 45 CFR part 16.
- (c) The Departmental Appeals Board also has jurisdiction to decide appeals brought by the States concerning any disallowances taken by the Secretary, or his or her designee, with respect to specific expenditures incurred by the States or by contractors or sub grantees of States. This jurisdiction relates to funds provided under the two formula programs—subtitle B of the Act-Federal Assistance to State Councils on Developmental Disabilities, and subtitle C of the Act-Protection and Advocacy for Individuals with Developmental Disabilities. Appeals filed by States shall be decided in accordance with 45 CFR part 16.
- (d) In making audits and examination to any books, documents, papers, and transcripts of records of SCDDs, the P&As, the UCEDDs and the Projects of National Significance

- grantees and sub grantees, as provided for in 45 CFR part 75, the Department will keep information about individual clients confidential to the maximum extent permitted by law and regulations.
- (e)(1) The Department or other authorized Federal officials may access client and case eligibility records or other records of a P&A system for audit purposes, and for purposes of monitoring system compliance pursuant to section 103(b) of the Act. However, such information will be limited pursuant to section 144(c) of the Act. No personal identifying information such as name, address, and social security number will be obtained. Only eligibility information will be obtained regarding the type and level of disability of individuals being served by the P&A and the nature of the issue concerning which the system represented an individual.
- (2) Notwithstanding paragraph (e)(1) of this section, if an audit, monitoring review, evaluation, or other investigation by the Department produces evidence that the system has violated the Act or the regulations, the system will bear the burden of proving its compliance. The system's inability to establish compliance because of the confidentiality of records will not relieve it of this responsibility. The P&A may elect to obtain a release regarding personal information and privacy from all individuals requesting or receiving services at the time of intake or application. The release shall state that only information directly related to client and case eligibility will be subject to disclosure to officials of the Department.

# PART 1386—FORMULA GRANT PROGRAMS

### Subpart A—Basic Requirements

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1386.2 Obligation of funds.

1386.3 Liquidation of obligations.